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Research that makes a real difference

Social Care for Marginalised Communities: Balancing self- organisation, micro-provision and mainstream support

Policy Paper 18 - February 2014

Sarah Carr

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Introduction

Adult social care works with some of the most disadvantaged people in society and social work has a tradition of inclusion, empowerment and anti-oppressive practice (Dominelli 2010). However, the reality is that a number of seldom heard groups experience aspects of mainstream, traditional social care provision as inaccessible or disempowering. Within the social care policy context of personalisation, adult social care and support needs to be more responsive to the increasing degrees of diversity among individuals, their communities and social networks. In terms of achieving the necessary flexibility and responsiveness, community-based micro-provision could be a particularly appropriate option for configuring social care support.

This briefing reviews recent research on two aspects of social care support provision for certain people with protected characteristics under the Equality Act 2010, who are often seldom heard in mainstream services. The review draws out messages for social care micro-providers and social care commissioners and focuses on the following two areas:

- the marginalising dynamics in mainstream, statutory social care support provision for certain people with 'protected characteristics' under the Equality Act 2010
- how local community, specialist or small-scale services are responding to unmet need for support and advice among marginalised groups

The aim is to establish an evidence base for commissioners and micro-providers or local community social enterprises wanting to offer services or specialist support to diverse communities or particular populations.

Summary and key messages for commissioners and providers

This paper reviews research from the UK published in peer-reviewed journals from 2000 to 2013 on:

- the marginalising dynamics in statutory, mainstream social care support provision for certain people with 'protected characteristics' under the Equality Act 2010
- how local community, specialist or small-scale services are responding to unmet need for support and advice among marginalised groups

The majority of research identified looked at issues and experiences of Black and Minority Ethnic (BME) communities, with a large number of studies dedicated to understanding the role of family carers, particularly from South Asian backgrounds. A smaller body of work on Lesbian, Gay and Bisexual (LGB) older people and carers was found. Similarly, a number of research studies on support for and by refugees and asylum seekers were identified. Some research on the role of faith was also found. By comparing research findings across

several groups, common issues about engagement with mainstream services and the function of community based and specialist support became apparent.

The findings from the review yield themes and messages for micro-providers, local community social enterprises and social care commissioners wanting to offer services or specialist support to diverse communities or particular populations.

The main themes and messages coming from the research for commissioners and providers are as follows:

1. Strategies for responding to marginalisation from the mainstream

- *Assets and community mobilisation*
People and communities who have found statutory, mainstream services problematic can be instrumental in finding appropriate solutions themselves. People from BME and LGB communities and refugees and asylum seekers have established their own specific support initiatives to address some of the gaps. This type of compensatory activity needs recognition and investment. Its existence does not imply the mainstream should not address the needs of these groups.
- *Reciprocity and social inclusion*
Small community-based initiatives can have benefits for the wider community in terms of social inclusion and cohesion, particularly for older people. Possible tensions can be limited by matching resources to community growth, especially in deprived areas with high competition for resources.
- *Informal networks and self-organisation*
Practical and emotional support for refugees and asylum seekers, LGB people and BME people can be generated through informally arranged peer support and social networks. Cultural assumptions and stereotyping means that self-organisation can be misunderstood by mainstream services and staff.

2. Accessing and engaging with mainstream provision

- *Fear of discrimination*
All groups had a perception or fear of mainstream social care services as being discriminatory or unsafe, which can lead to a reluctance to engage. People from BME and LGB communities sometimes avoid using mainstream services to maintain control of their lives and identities or to avoid feelings of stress and powerlessness. Trust is a complex issue.
- *Uniformity and homogenisation*
The use of administrative categories in mainstream services can lead to stereotyping and homogenisation of BME and LGB people. 'Diversity blindness' as an approach to equality limits the degree to which mainstream support can respond appropriately to particular groups.

- *Language and communication*

Major challenges still concern language barriers for those who are not fluent in English and the effectiveness of interpretation or communication methods. Fear may prevent older LGB from communicating personal history and identity.

3. Relationship dynamics between large, traditional mainstream and small, specialist community

- *Specialised knowledge and scale*

Partnerships need to be explored but the uniqueness of small specialist and community organisations needs to be maintained, particularly as regards cultural intelligence and values.

- *Capacity building and partnerships*

Local, community-based specialist organisations for marginalised people often face challenges relating to capacity building, funding, sustainability and infrastructure. Groups are often competing with each other for funding and lack ability to access funding owing to lack of capacity and skills.

- *Proportionate processes*

Statutory administrative processes and regulation are a restricting factor for the sustainability of specialist community-based support or innovative initiatives.

- *Advocacy and accessing mainstream support*

Specialist community initiatives can help access to and awareness of mainstream support. They can also help mainstream services to develop capacity around communication and cultural competence.

- *Choice and voice*

While specialist community-based support can offer choice, mainstream services should not abdicate responsibility for BME people, LGB people and refugees and asylum seekers to specialist services alone. Community support groups can potentially offer marginalised people a collective voice and improve a sense of agency.

4. Understanding informal support in diverse communities

- *Complexities and cultural stereotyping*

Mainstream services and staff can make unhelpful assumptions about race, culture and family caring patterns. Networks of support can be broader and more complex than the immediate family. For LGB people friends may have an important role in providing support.

- *Culture, stigma and shame*

Stigma and shame can arise in relation to 'illness' (particularly mental health problems) and service use for some BME people and people from certain cultures or faith communities.

- *Well-being, identity and resilience*

Faith and cultural tradition can be a positive factor for maintaining identity, resilience and well-being. Attachment to communities of culture and identity,

rather than geographical place, can be important for LGB people and for refugees and asylum seekers.

- *Culture and faith*

Faith can help some BME people and refugees and asylum seekers with resilience and to make sense of life situations, disability or illness. Faith and culture can generate effective informal support for some people and can be an important source of social capital, although simplistic approaches to complex matters of faith and religion are unhelpful.

5. Effective approaches

- *Emotional and social support*

Grassroots and support network initiatives for marginalised people are multi-dimensional and can offer a mixture of instrumental, social and emotional support. Self-help and mutual support approaches can draw on the tradition of mobilising social capital in marginalised communities.

- *Non-conventional, networked and holistic support*

Small community-based support initiatives can integrate non-conventional or broader support and activity sources for individuals and communities in a way mainstream services often cannot.

Background

Recent social care policy and implementation strategies as outlined in 'Capable Communities, Active Citizens' and in the Think Local Act Personal (TLAP) partnership agreement, emphasise that increasing choice and control and building community capacity are inter-related personalisation policy objectives (DH 2010; TLAP 2011). The National Care Forum, part of the TLAP partnership, has argued the case for the distinctive contribution that local not-for-profit support providers can make to added value and social capital in social care, as well as improving choice (IPC 2012). Community Catalysts, an organisation that provides practical support and advice to micro-providers, has argued that people who have experienced care and support services are well placed to 'spot any gaps in services and supports within their community and could be well placed to fill these gaps' (Community Catalysts 2011 p3).

In their baseline survey of micro-providers, Bull and Ashton (2011) found that the majority offered specialist support and were established to help people and communities in a local area. Dickinson et al (2012) argue that new types of social care support provision, such as micro-providers and small community social enterprises should increase as a result of personalisation. Such local support is to scale and can have the flexibility, responsiveness and quality of relationships required by people who use social care and support. In terms of building community capacity such 'bottom-up' developments can draw on unique cultural intelligence, building on individual and collective assets, knowledge, networks and strengths. However, it has been noted that 'smaller entities are sometimes much more vulnerable than their larger counterparts and commissioners may want to help these organisations come together collectively' (Dickinson et al 2012 p28).

Adult health and social care reforms are occurring within the wider equality and diversity policy framework, with the Equality Act 2010 underpinning public policy developments and defining those with 'protected characteristics' under the Act. The Health and Social Care Act 2012 legislates for the duty to reduce inequalities in health and social care. Research continues to show that people from particular minority groups or those with 'protected characteristics', such as black and minority ethnic (BME) people or lesbian, gay and bisexual (LGB) people, remain marginalised by mainstream services in social care and mental health (Chahal 2004; Ward et al 2010). It has been argued that by using personal budgets and direct payments people who are marginalised by the mainstream can purchase culturally appropriate support and improve choice in local social care markets (Voice4Change 2012). Some local authorities with a high density populations of BME communities or LGB people have made efforts to engage with those communities to understand their needs and support networks better (Carr & Ross 2013). In this policy context, the necessary flexibility and responsiveness could be achieved by further developing community-based micro-provision as a social care and support choice.

Methods and scope

The research review is not all-inclusive or definitive, but aims to identify common themes and approaches as well as distinct experiences between groups. While it is not a systematic review, it has been systematically conducted some and is informed by Greenhalgh and Peacock's (2005) model of searching for complex evidence. The methodology is guided by the 'narrative review' approach and the studies included have been subject to thematic analysis.

Searches were conducted for empirical research or research review (including systematic review) papers focusing on the UK that were published in English in peer-reviewed journals about social care service provision for working age adults and older people, including carers, from 2000 to 2013. The groups or topics covered in the search strategies were: black and minority ethnic people; lesbian, gay, bisexual and transgender people; older people; carers; religion and belief; refugees and asylum seekers. Eighty-five papers were initially identified and after screening, forty-five peer-reviewed journal research papers were finally included.

Overall, the research evidence on the effectiveness of local community, specialist or small-scale services is patchy but indicates that information, care and support initiatives are developing in response to actual or perceived difficulties with mainstream provision. There were very few specific service evaluations and none explicitly on small private or not for profit micro-providers or social enterprises. However, evidence is also beginning to show the potential of self-help groups, local mutual-aid projects and the importance of maintaining social support networks for well-being and identity, particularly for BME and LGB older people. There are particular messages emerging from the research about the experiences of carers from minority groups. By comparing research findings across several groups, common issues about engagement with mainstream services and the function of community based and specialist support become apparent.

The findings from this research review yield messages for micro-providers, local community social enterprises and social care commissioners wanting to offer services or specialist support to diverse communities or particular populations.

Key themes and findings

The majority of research studies identified looked at issues and experiences of BME communities, with a large number of papers dedicated to understanding the role of family carers, particularly from South Asian backgrounds. Other BME groups covered in the research included Irish people, Somali people, Ethiopian people and Chinese people. No study was found specifically on Black African or Caribbean people in the UK although findings for this group appear in several of the generic BME research reviews. A smaller body of work on LGB older people and carers was found. Similarly, a number of research studies on support for and by refugees and asylum seekers were identified. Some research on the role of faith was also found. Finally, a number of evaluations for specific initiatives were identified and included. Because of their particular relevance to the review, one study from Australia and two studies from Ireland were included. Although the search strategy and selection criteria had limitations, the exercise suggests that there are gaps in the UK research published in peer-reviewed journals in English for gypsies and travellers, transgender people and for people who might experience multiple discrimination such as LGB people from BME communities.

Reviewing a body of research encompassing several groups who tend to be marginalised by mainstream social care and support allow the experiences of those groups to be compared in more detail and for commonalities to be identified. The structure for the discussion below is based on clustering key themes and findings coming from the analysis of the research, under the following thematic headings:

- Strategies for responding to marginalisation from the mainstream
- Accessing and engaging with mainstream provision
- Relationship dynamics between large, traditional mainstream and small, specialist community organisations
- Understanding informal support in diverse communities
- Effective approaches

Strategies for responding to marginalisation from the mainstream

Assets and community mobilisation

When viewed from an asset-based approach (Kretzmann & McKnight 1993), it is apparent that people and communities who have found traditional, mainstream services inappropriate or problematic to engage with, can be instrumental in finding appropriate solutions themselves. BME communities have established

specific care and support initiatives to address some of the gaps (Manthorpe et al 2010; Truswell 2011; Moriarty 2008; Cant & Taket 2005; Sin 2006). Similarly, LGB people as well as asylum seekers and refugees have found compensatory ways to support themselves through social networks and peer support (Williams 2006; Heaphy et al 2003; Drummond 2002; Papadopoulos et al 2004; White & Cant 2003; Daley 2007). For both groups this is especially apparent in the research for older people, carers, dementia and adult mental health. The literature therefore suggests a tradition of mobilisation of social and community resources, self-organisation and informal social support, something which is also emerging for micro-provider activity (Bull & Ashton 2011; Community Catalysts 2011).

However, it is clear that such activity and provision needs capacity building, funding and infrastructure while maintaining its uniquely responsive, local, grassroots nature. As one research commentary noted for older BME people: 'community-based voluntary service organisations provide a valued service, and...failure to maintain this support also results in further isolation of older people' (Desai 2012 p86). Elsewhere a study into home support for older South Asian people based in Scotland found that 'more user-focused approaches and grassroots involvement may offer ways forward, despite some limitations of current models' (Bowes 2006 p739). So it is also apparent that the types of compensatory activity identified in the research needs recognition and investment, and that its existence does not imply that the mainstream should not address marginalisation. A study of the social care and support expectations of Asian-Indian older people suggested that 'it must...not be assumed that simply because someone is not accessing state support at the moment that the individual thinks that the state does not need to provide these sources of support' (Sin 2006 p222).

Research suggests that informal networks and small community services are important for combating isolation and ensuring that older people, (including those with dementia) remain supported in rural areas where access to mainstream services can be problematic (Walsh & O'Shea 2008; McDonald & Heath 2008). A study of rural dementia support in Eastern England concluded that 'very local services that had grown up to meet particular needs are...celebrated for their sensitivity to older people's sense of security and belonging' (McDonald & Heath 2008 p17).

Reciprocity and social inclusion

Small community-based or local initiatives have been found to have benefits not only for the users of the service but for the wider community in terms of social inclusion and social cohesion, particularly for isolated older people. One study based in rural Ireland showed the wider impact of an older people's group project providing innovative 'intergenerational and intercultural projects, drama, health initiatives, life-long learning, holidays and social events' as well as more traditional 'transport, laundry, chiropody, outreach service, information sessions and information technology tutorials' (Walsh & O'Shea 2008 p797). The intergenerational and intercultural activities were effective in promoting social cohesion and interaction with the local traveller community, many of whom initially became involved through a choral group. The study reflects findings

from similar project evaluations on empowerment, reciprocity and compensation (Seeböhm et al 2013):

‘In an organisation working for a marginalised section of the population, it is noteworthy that empowerment is embedded as a central element of the group’s activities...[the project] has succeeded in nurturing a viable social care community... where people do things for themselves and others. This community model compensates for the absence of public provision. Older people make a difference to social care provision and quality of life within [the locality] and its rural environs’ (Walsh & O’Shea 2008 p802)

However, to balance these findings on social cohesion and inclusion, research into refugee integration and community groups in a densely populated urban area concluded that ‘adequate resources and social infrastructure for all residents were seen as necessary for cohesion and therefore matching resources and services to community growth is the key to limit the build up of community tension, particularly in areas of existing deprivation and high competition for resources’ (Daley 2007 p168)

Informal networks and self-organisation

Research shows that practical and emotional support for refugees, asylum seekers and Somali older people is accessed through peers and social and community networks, often informally arranged (Silveira & Allebeck 2001). A study examining the tactics of refugees and asylum seekers for meeting their practical and emotional needs suggests that refugees reported ‘reluctance to trust the advice of statutory services without first checking that advice with other refugees with first-hand experience’ (Williams 2006 p875). Again, the research indicates specific issues with capacity building, particularly when ‘most refugee organisations...are not formally structured and so cannot take up funding opportunities’ (ibid p.877). Compensatory self-organisation is also apparent in the literature for the Chinese community in the UK, for South Asian carers and for LGB older people, but it also shows that cultural assumptions and stereotypes of ‘families’ mean that such self-organisation can be misunderstood or misinterpreted by mainstream services and staff, possibly leading to a lack of appropriate formal support provision (Cronin et al 2011; Price 2012; Heaphy et al 2003; White & Cant 2003; Sin 2006; Yueng & Ng 2010; Katbamna et al 2004; Victor et al 2011).

Accessing and engaging with the mainstream

Fear of discrimination

A consistent finding across all groups was a perception or fear of mainstream, traditional care and support as discriminatory which can lead to a reluctance to engage. In his comparative study of the expectations of support among White British and Asian-Indian older people in Britain, Sin (2006) notes that ‘a persons’ perception of the adequacy or quality of support is inevitably influenced by his or her expectations of the type, frequency and source of support preferred or

required' (p216). Here, it is interesting to note that this was true for BME communities, LGB people, people from certain faith groups and asylum seekers and refugees, as the research studies suggested that all feared discrimination or misunderstanding, had low expectations of the suitability or accessibility of support and even feared interventions from large, generalist or mainstream providers (Price 2012 & 2010; Mir & Tovey 2003; Sin 2006; Yeung & Ng 2010; Cronin et al 2011; Papadopoulos et al 2004; Heaphy et al 2003; Williams 2006; Chau & Yu 2006).

This perception or experience of the mainstream led some LGB people and carers from BME communities to avoid using traditional services in order to maintain control over their lives and identities or to avoid stress and feelings of powerlessness (Mir & Tovey 2003; Sin 2006; Price 2012 & 2010). A study on South Asian parents of adult children with cerebral palsy found that 'feelings of inability to influence or control the response from services led parents to avoid initiating contact' (Mir & Tovey 2003 p472). Similarly, a study of the LGB carers of LGB people living with dementia showed anxiety and stress in accessing mainstream support particularly because 'privacy was something all respondents valued and strived to maintain and many people feared for a future where such control was no longer possible' (Price 2012 p523). Research is beginning to suggest that mainstream, traditional services are often not trusted and that building trust can be complex (Cant 2002)

Uniformity and homogenisation

The studies suggested some reasons for the perception or experience of discrimination and misunderstanding in mainstream, traditional services which can lead to non-engagement or disengagement. Again, for both BME communities and LGB people (and in some cases for refugees and asylum seekers) there were consistent findings about stereotyping and assumptions; homogenisation; diversity blindness and universalism; and the limiting nature of categorisation. Such issues with practice and service provision influenced the degree to which mainstream, traditional support was perceived or experienced as accessible and suitable. For example, a study on the consequences of using administrative categories leading to homogenisation for LGB older people suggested that it is important to: 'recognise the fact that LGB people do not simply constitute one easily defined, socially homogenous group whose needs are similar simply by virtue of membership' (Cronin et al 2011 p425). Likewise, stereotyping and homogenisation was identified as a difficulty for Chinese people when engaging with mainstream social care and support: 'it is important to note that the extent to which members of the same ethnic-minority group characteristics many undermine our understanding of culturally diverse groups' (Chau & Yu 2009 p775).

A related theme strongly apparent in the literature was that of diversity blindness and universalism; again particularly problematic for both BME communities and LGB people (Cronin et al 2011; Batsleer et al 2003; Chau & Yu 2009). This approach limited the degree to which mainstream support could respond in a culturally sensitive way or could accommodate the particular support needs of the individual in the context of personalisation in adult social care (TLAP 2011). To exemplify this, a study concerning the responses of health and social care

staff to South Asian women who self-harm or who have attempted suicide identified several types of 'neutrality' in practice as having an impact on the quality and accessibility of support: 'First there is the "race neutral" or universalist approach. The second approach can be termed the "gender neutral" approach, in which issues of "race" and culture are privileged over all other issues in the form of supposedly "ethnosensitive" services (Batsleer et al 2003 p109). An additional dimension to diversity blindness or neutrality can be identified for older LGB people where 'sexuality blindness' leads to invisibility and difficulties around feeling safe and 'coming out' (Price 2010). While focusing on LGB older people, Cronin et al (2011) make an important generalisable point about neutrality and equality in mainstream social care: 'a..."blind" approach, although reasoned by service providers as equal treatment, [is] somewhat difficult to justify' (p424) in the context of personalisation and the Equality Act 2010 (Ward et al 2010).

Language and communication

Language and communication remain enduring difficulties for people from BME communities and for refugees and asylum seekers when accessing mainstream social care services (Moriarty 2008; MacFarlane et al 2009; Merrell et al 2006). The research shows that the major challenges still concern language barriers for those who are not fluent in English and the effectiveness of interpretation methods (MacFarlane et al 2009; Merrell et al 2006). One study of language barriers in social care and interpretation services indicated the need for sensitivity about confidentiality, trust and anonymity if using community-based interpretation services: 'while strong local networks have advantages for well-being in terms of social capital, there may be disadvantages in terms of a "goldfish bowl" effect' (MacFarlane et al 2009 p209).

Newer research suggests that people with dementia can have communication difficulties for decision-making that can be potentially addressed through technologies such as Talking Mats (Murphy & Oliver 2013). Although the research was limited to LGB older people who spoke English as a first language, findings on fear of discrimination and concern for safety suggest that there may be a communication issue for this group. The issue concerns not how things are communicated, but what is communicated. Research shows that fear may prevent older LGB people from disclosing personal history and identity that can affect quality of decision-making and care and support, especially for LGB people living with dementia and their carers (Price 2012; Price 2010; Cronin et al 2011).

Relationship dynamics between large, traditional mainstream and small, specialist community organisations

Specialised knowledge and scale

A significant theme coming through a sub-set of the literature was the relationship dynamic between large mainstream, generalist services (either in the statutory or charity sector) and small, local specialist and community support activity, particularly for BME communities and refugees and asylum seekers. The recommendation in some of the research about the need to explore and develop partnerships in order to develop capacity was qualified with a warning about maintaining the uniqueness of small specialist and community organisations, particularly as regards cultural intelligence and values (Truswell 2011; Radermacher et al 2011; Seebohm et al 2013; Drummond 2002). This was especially apparent in a paper on BME and refugee communities and the implementation of the UK National Dementia Strategy in London for what are described as 'fourth sector organisations': '...very small and highly specialised voluntary organisations...with substantial highly specialised skills and information. These organisations required the support of the larger third sector to gain funding, but risked losing their specialised skills and unique contributions if they were permanently absorbed into larger organisations' (Truswell 2011 p117)

A specific example of this came from an Australian study looking at 'inter-organisational partnerships in the multicultural community aged sector' (Radermacher et al 2011) which showed that in some cases 'because of specific cultural customs (e.g clients giving staff gifts, which if not accepted can be regarded as offensive to clients), certain activities and practices may not always be condoned or understood by bigger, mainstream organisations' (Radermacher et al 2011 p558). The study also indicated that the current service system favours big organisations with larger capacities and yet because of their scale such services may not have the 'specific and unique skills and experiences' of the small, community based support organisations for older BME people. Similar concerns about small, local self-help initiatives partnering with large national charities arose from research into specialist self-help/mutual aid projects in England: 'Eight groups were affiliated to national charities to get support and status. Relationships varied from inspirational to indifferent or worse for three groups who found that their national charity failed to appreciate the group's voluntary ethos' (Seebohm et al 2013 p398). Based on their research findings, Radermacher et al (2011) recommend that

'these smaller organisations...have vast expertise in delivering culturally appropriate care, and have strong links with their community. Assistance with how to promote their strengths and build on them in a proactive way through the initiation of appropriate partnerships could be very useful...in the longer term' (ibid p558)

Capacity building and partnerships

The literature shows that there are issues about capacity building, funding, sustainability and infrastructure for small local, often specialist organisations and projects for people marginalised in mainstream adult social care and support provision (Truswell 2011; Walsh & O'Shea 2008; Radermacher et al 2011; Bowes 2006; Seebohm et al 2013). Some of the difficulties are inherent in the 'top-down' partnership dynamics with large mainstream agencies and national charities, as discussed above. The research showed that for small organisations in the BME and rural voluntary and community sector, groups are often competing with each other for funding and lack resources or lack access to funding owing to capacity and skills (Truswell 2011; Walsh & O'Shea 2008; Bowes 2006). This then impacts on the sustainability and capacity of the organisations and their projects.

The ability to apply for and access local authority or health funding related to constitutional issues, skills, time, structure and size along with funding application processes and requirements. This was found to be a particular difficulty for specialist self-help groups: 'many groups wanted assistance with fund-raising and practical matters, especially where there was no specialist support for self-help groups' (Seebohm et al 2013 p398). Radermacher et al (2011) note that 'smaller organisations reported they were primarily occupied with direct service delivery and administrative tasks' (p555), that limited their capacity for partnerships and fundraising and risked inequalities in partnership working. The study concluded that 'the current service system favours bigger organisations with larger capacities.

While smaller organisations may have visionary and charismatic leaders, their influence is limited because of the structural status quo' (p558). An evaluation of a specific community-based project for isolated older people in rural Ireland concluded that capacity building and skills development was important for sustainability: 'one of the major problems facing the organisation is...to widen and deepen the organisational and management skills...while maintaining its volunteering ethos and local connections' (Walsh & O'Shea 2008 p803). Bowes outlines the tensions experienced by South-Asian community based groups, where the organisations 'demonstrate on one hand that responsive services can be developed at local level, but that on the other, such groups experience exclusion from the general service provision systems. Marginal funding, insecurity and reduced regulation all served to restrict the potential of these groups' (Bowes 2006 p751). Watters and Ingleby (2004) found similar conclusions for UK refugee and asylum seeker support which they argue is often ad hoc and short-term: 'a further problem for both black and minority ethnic groups and refugees is that specialised services targeting these groups often take the form of short-term projects' (p556).

Proportionate processes

Mainstream administrative processes and regulation were found to be a potentially restrictive factors for the sustainability of small, specialist community based social care initiatives (Bowes 2006; Bernard 2005; Seebohm et al 2013). Bowes demonstrates this for South-Asian community groups where 'there was

evidence that they were not subject to the same monitoring and inspection as other contracted-out service providers, and, at least partly because of this, were not receiving the support local authorities could have offered them' (Bowes 2006 p751). One of the few evaluations of an innovative social care and support approach looked at recruitment and retention of carers in adult placement schemes in England. While adult placement schemes attracted higher numbers of carers from South Asian backgrounds than in the general social care workforce, in general the 'most common reason for recruitment difficulties experienced by the schemes was the burden of regulatory requirements and was cited...as the main reason for retention problems' (Bernard 2005 p566). Seeböhm et al (2013) found that although mental health self-help groups can be effective, their development can be problematic as they 'are little understood and do not fit easily within a regulated health sector' (p400). So it appears that disproportionate regulation and service categorisation may be restricting some specialist BME community organisations and impacting on an innovative mainstream approach that seems attractive to a particular BME community.

Advocacy and accessing mainstream support

While the research shows tensions between larger, traditional mainstream provision and smaller, specialist community support initiatives, it also demonstrates the value of these organisations for supporting access to and awareness of mainstream support and for mainstream services to develop capacity around communication and cultural competence (Mir & Tovey 2003; Yueng & Ng 2010; Papadopoulos et al 2004; Merrell et al 2006; Cant & Taket 2005; Manthorpe et al 2010; Moriarty 2008). Studies suggest that user and carer groups can be instrumental in providing support for people from South-Asian and Chinese communities to be aware of available mainstream services and to influence how that support meets the needs of the particular group (Mir & Tovey 2003; Yueng & Ng 2010). A study of the health and social care experiences of Ethiopian refugees and migrants in the UK showed that 'participants reported Ethiopian community organisations often played a crucial role in advocating for them and helping them access statutory services (Papadopoulos et al 2004 p64). Research by Merrell et al (2006) points to the importance of advocacy and link work for Bangladeshi carers in Wales who were found to be a hidden population experiencing inequity in service provision. A similar information and advocacy function was found to be supportive for older Irish people accessing statutory mental health services and welfare benefits (Cant & Taket 2005). Likewise, community-based mainstream support services were found to facilitate access to mainstream support services for BME older people, including those living with dementia and their carers (Manthorpe et al 2010; Bowes 2006; Sin 2006; Moriarty 2008; Truswell 2011).

A particular aspect of advocacy and link working in the research focused on language and access to mainstream support and information. As already noted, for some BME communities and refugees and asylum seekers, language can be a significant barrier to awareness and access (Moriarty 2008; Merrell et al 2006; MacFarlane et al 2009; Yeung & Ng 2010). While Yeung & Ng (2010) draw attention to the role of independent bilingual 'trusted intermediaries' in the research, MacFarlane et al (2009) caution about stigma and confidentiality where interpreter service users 'voiced their concern that the interpreter may be known

to them and may be someone with whom they did not want to share private health issues' (p209). In order to address some of these complexities around community and confidentiality Williams et al (2007) suggest that BME social welfare organisations and user groups are 'ideally positioned to provide other sectors with culturally competent service models' (p197).

Choice and voice

UK adult social care policy determines that people should have choice and control over their care and support, which clearly implies social care market diversification and involvement in local planning and commissioning (IPC 2012). Having a range of support and advice services appropriate for local populations is important for achieving this, especially where those populations are diverse or if there is a high density of BME or LGB people or refugee and asylum seekers living in the locality. However, research here suggests that mainstream, traditional services should not abdicate responsibility for these groups to specialist services alone (Bowes 2006). While some are very supportive of the idea of specialist services, other LGB older people have expressed anxiety about 'ghettoisation' if specialist services are their only choice and mainstream support continues to be inaccessible (Price 2012). Bowes (2006) concluded that 'while...community-based South Asian groups provided important and effective services...they do not necessarily represent all those who need service support' (p753). A research review of the health and social care experiences of BME older people found that although 'people from BME groups reported better experiences from services that specialised in supporting people from minority ethnic groups...if commissioners relied only upon specialist services, this could discourage them from making improvements to mainstream services' (Moriarty 2008 p5).

Small local community support groups can potentially offer marginalised people a collective voice and improve their sense of agency in training, service development and commissioning. Research shows that this can be true for older BME people (including those living with dementia) and refugees and asylum seekers (Truswell 2011; Moriarty 2008; Yeung & Ng 2010; Daley 2001). For refugees and asylum seekers, some research reveals issues with trust and engagement with mainstream community participation initiatives which can be addressed through specialist community organisations (Daley 2001). Infrastructure organisations or umbrella groups have been noted in the literature as helpful for building capacity both in the community sector and for improving mainstream access to advice on cultural competence and 'hidden communities', such as BME older people (Manthorpe et al 2010). Research evidence suggests that the self-help/mutual aid group model can offer participants the opportunity to 'influence and be heard', an outcome that is linked to enhancing feelings of control and self-determination (Seeborn et al 2013).

Understanding informal support in diverse communities

A consistent theme coming from the literature was the need for traditional and mainstream social care and support to understand and accommodate the sometimes complex nature of informal support for BME communities, refugees and asylum seekers and LGB people (Merrell et al 2006; Sin 2006; Victor et al 2011; White & Cant 2003; Heaphy et al 2003). Such informal support can be identified in the research as family, friends, communities of culture, faith and identity and other types of informal social networks. The difficulties associated with stereotyping, homogenisation and assumptions already discussed were also found to be particularly relevant for understanding informal support and appropriate services for carers. Research also indicates the role of specific cultural interpretations of illness or disability and in influencing attitudes to formal 'state' support (Merrell et al 2006; Chau & Yu 2009; Mir & Tovey 2003; Papadoupoulous et al 2004; Silveira & Allebeck 2001; Cant & Taket 2005).

Complexities and cultural stereotyping

There was a message from the research about the effects of mainstream assumptions about race, culture and family caring patterns, particularly for South Asian people who can be caricatured as completely self-reliant. For example, a study on South Asian family caring found that the main family carer (usually female) did not necessarily have access to extended family support, concluding that 'the findings challenge the pervasive assumption and stereotype that South Asian people live in self-supporting extended families, and therefore, that the support of social services is largely unnecessary' (Katbamna et al 2004 p404). Research into Bangladeshi carers also found that misunderstanding and cultural stereotyping contributed to 'differential practice being delivered' and that there was a lack of appropriate outreach (Merrell et al 2006). Another study suggested that 'most Asian-Indian families tend to see state support as a poor substitute for family support' (Sin 2006 p220). Based on their research findings, Victor et al (2011) recommend that: 'social care-based services may be more appropriate and acceptable if they focus on helping and supporting families to care rather than being viewed as substitutes for family care' (p92). Several studies showed complex, global webs of family relationships or 'superfamilies' (Sin 2006) for certain BME communities and for refugees and asylum seekers, also with particular implications for support and advice services (Victor et al 2011).

Although Victor et al (2011) assert that for South Asian communities 'friends were not seen as an appropriate source of direct care and, again, this is the case with the wider population' (p404), this contrasts with research findings about the role of friends (as well as same-sex partners) in care and support for LGB people (White & Cant 2003; Heaphy et al 2003). Again, the research shows that understanding informal support for older LGB people can be subject to assumptions and stereotyping by mainstream services and can effect carer engagement, confidence and help-seeking behaviour (Price 2012 & 2010). A study on support networks of HIV-positive gay men found that 'partners, ex-partners and friends were likely to be seen more frequently than family members,

and therefore, are more able to offer daily emotional and instrumental support' (White & Cant 2003 p331). The same was found for older LGB people, where 'friends are on a par with partners and family in terms of material support in times of need' and 'few expect family members to assume this [care and support] responsibility' (Heaphy 2003 p33). The pressure on partner carers of older LGB people with dementia to 'come out', disclose or not hide their same-sex relationship status to mainstream services was found in several research studies to be a source of anxiety and in some cases discrimination, thereby resulting in mainstream support being inaccessible or of poor quality (Price 2012 & 2010). One study concluded that a key difficulty lay in 'how caring...[is] framed in accordance with heteronormative social relations' (Cronin et al 2011 p427).

Culture, stigma and shame

Another research sub-theme is the cultural issue of stigma and shame among some BME communities and among refugees and asylum seekers, requiring particular cultural awareness and sensitivity and influencing mainstream service use. For BME older people 'the existence of stigma, particularly about mental health problems in old age, may be higher in some communities than in others' (Moriarty 2008 p3). The issue of confidentiality and mental health stigma was found in research on orthodox Jewish people in the UK, South Asian people, Irish older people and for Somali older men (Loewenthal 2012; Silveira & Allebeck 2001; Cant & Taket 2005). Yeung and Ng (2011) conclude that 'the cultural issues about shame, losing face and other traditional Chinese beliefs...need to be thought through carefully when planning [for] this marginalised community' (p294). Further complexities around mental health, stigma and gender was found for South-Asian women (Batsleer et al 2003). Stigma and shame were found to arise in relation to 'illness' and to formal service use for some BME families (Sin 2006), as Victor et al (2011) note for carers from South Asian communities in the UK: 'having to turn to the state for care was clearly construed extremely negative...indicating lack of family loyalty and potential loss of face within the wider community' (p90). This finding also appeared in Lowewenthal's (2012) study of orthodox Jewish people and mental health support.

Caution around the use of specialist community support and family or close community interpreters was recommended in some studies as compromising confidentiality which was felt to be a risk for families and individuals where mental health was an issue (Batsleer et al 2003; Lowewenthal 2012; Seeböhm et al 2013; Yeung & Ng 2010; Merrell et al 2006; MacFarlane et al 2009). As Lowewenthal puts it, 'culturally sensitive services within communities involve a different set of problems - the risk that problems may become public knowledge' (2012 p164).

Well-being, identity and resilience

The research showed that informal support is not restricted to people or networks providing informal, instrumental or personal 'care' (Cant 2002; Manthorpe et al 2010). For some BME people, including refugees and asylum seekers, faith, belief and cultural tradition can be a positive factor for resilience, well-being and for interpreting illness or disability (Mir & Tovey 2003;

Papadopoulos et al 2004). Maintaining links to community of culture and identity was also found to be important for the quality of life and well-being of older LGB people, with research indicating that 'lesbian and gay groups or communities [are] important sources of support and provided a means of maintaining a gay or lesbian identity and way of living' (Price 2012 p525). Attachment to communities of culture and identity, rather than geographical place, and maintenance of identity and well-being was also found in the research for refugees and first generation migrants from Ireland, Somalia and Ethiopia. For older Somali men at risk of depression, social gatherings and reminiscence were important for reducing isolation and promoting mental health: 'such practices, Somali based on shared cultural, religious and moral values contributed to a strong sense of personal identity' (Silveira & Allebeck 2001 p313). Specialist, community-based initiatives appear to be important for 'offering a place where patterns of cultural specificity [are] part of the everyday life of the project' (Cant & Taket 2005 p265).

Culture and faith

Research into the experiences of Bangladeshi carers suggested that they were sometimes reluctant to seek help for personal care from mainstream, traditional sources because there was a perception that these services would be 'unable to meet their cultural and religious needs' (Merrell et al 2006 p203). Similar conclusions were reached for other BME communities and for LGB people (Moriarty 2008; Price 2012 & 2010). Evidence suggests that faith and culture are important for resilience and well-being. Networks of initiatives which can encourage this type of support should be recognised as an important source of 'social capital' and an asset. However, research also shows complexity and tension when it comes to faith and religion in support services (Hopkins 2011; Daley 2007). Simplistic approaches to religion and faith or assumptions that faith-based projects can unproblematically provide support are unhelpful (Lowewenthal 2012, Chau & Yu 2009, Batsleer et al 2003, Furness & Gilligan 2010). For example, for South Asian women's mental health 'misinformed ideas about "culturally sensitive services" in relation to religious faith and spirituality can lead to a denial of the issues of attempted suicide and self harm' (Batsleer et al 2003 p110). Understanding diversity of belief within a BME community is highlighted in the research on Chinese people: 'ethnic minority groups have diverse ways of connecting their lifestyles to their heritage and...their cultural beliefs are not monolithic' (Chau & Yu 2009 p775).

Several research studies showed the importance of faith for resilience and making sense of life situations, disability or illness for some BME people and refugees and asylum seekers. Evidence suggests that the use of faith to interpret difficulties is not always recognised or understood by general, mainstream health and social care services (Furness & Gilligan 2010). Using belief systems to interpret and manage mental health was a particular theme in the literature, with Papadopoulos et al (2004) reporting this for predominantly Christian Ethiopian refugees in the UK and Lowenenthal (2012) noting this for Orthodox Jewish people living in England. For South Asian carers, faith was found to have a potentially positive role to play in understanding and managing their circumstances as well as boosting emotional resilience (Mir & Tovey 2003).

Effective approaches

The literature research for this review yielded very few formal evaluations of specialist or small community-based support services aimed at people marginalised in mainstream, traditional services. However, some of the studies point to particular approaches and practices which could be effective for delivering appropriate and acceptable care and support and to inform the development of micro-providers and community social enterprise in social care.

Emotional and social support

Most of the grassroots and support networks for BME communities, LGB people, older people living in isolated rural areas and refugees and asylum seekers alike are multidimensional or holistic in their support provision (Cant & Taket 2005; Manthorpe et al 2010, McDonald & Heath 2008; Cant 2002; Cronin et al 2011; Walsh & O'Shea 2008; Drummond 2002, Seebohm et al 2013). Cant describes social support that is beneficial to health and wellbeing as being 'primarily emotional or primarily instrumental...[or] a mixture of both' (2002 p1). While mainstream, traditional services tend to focus mainly on instrumental support, emotional and social support was seen as equally important by all groups included in this review and this is prioritised or balanced in the specialist community-based support projects in the research. One approach to support provision which emerged from the research as being promising for was the self-help or mutual model (Cant & Taket 2005; Walsh & O'Shea 2008; Seebohm et al 2013). Seebohm et al's (2013) study of self-help organisations, including those for BME people, in Essex and Nottingham suggests that

'the groups improved mental well-being, benefiting individuals and creating community-based resources. Participants controlled groups activities, gained self-esteem and knowledge, enhancing scope for self-determination and choice...Giving was important, helping members to gain a sense of belonging and being involved' (p398).

Similar findings come from a study of a user-led project for older people in rural Ireland and from research into an Irish pensioner's project in London (Walsh & O'Shea 2008; Cant & Taket 2005). The literature in this review has suggested that members of marginalised communities often utilise their own social network resources for support, and the grassroots mutual approach can build on this tendency and recognise it as an asset.

Non-conventional, networked and holistic support

Another dimension to small or specialist community support is that it also contrasts with the mainstream by integrating non-conventional, informal and broader support sources for individuals and communities. This was a theme coming from several studies, particularly for those focusing on projects for older people living in rural areas and for those from BME communities (Walsh & O'Shea 2008; McDonald & Heath 2008; Manthorpe et al 2010). Research

into the development of services for people living with dementia in a rural area concluded that ‘examining [very local] services in rural areas attenuates many aspects of providing person-centred care...it requires a whole-systems approach to service, which includes looking at transport and leisure services as well as at health and social care and how they interact within a community’ (McDonald & Heath 2008 p17). Similarly, Manthorpe et al (2010) located effective mental wellbeing activity for older people from BME communities not within traditional mental health services, but within ‘voluntary and community groups, sheltered housing, day care and care management’ (p34). Sin (2006) argues that for Asian-Indian older people living in Britain there needs to be a greater understanding of ‘the interdependence of formal and informal spheres’ of support. A study into the relationship between unmet needs, social networks and quality of life of people living with dementia at home found that while most had ‘physical and environmental needs met by services, psychological and social needs were more likely to be met by those with higher community-involvement social networks’ (Miranda-Castillo et al 2010 p1).

Conclusion and recommendations

In order to inform the development of micro-provision for an increasingly diverse society, this briefing examined some recent research on how certain groups with ‘protected characteristics’ under the Equality Act 2010 (or seldom heard groups) have experienced mainstream provision. Research about BME people, LGB people, refugees and asylum seekers and people from faith communities was identified and examined to discover how local community, specialist or small-scale services are responding to unmet need for support and advice among these seldom heard groups. While each group had their own particular issues, there were common experiences and responses, most notably self-organisation and mobilisation of social capital to compensate for gaps in mainstream support provision. Personalisation policy in adult social care is explicit about increasing choice and control over care and support and about building community capacity as part of this (TLAP 2011). While this research review is limited and could not include all seldom heard groups (partly because research could not be identified), the findings reveal some important recommendations for micro-providers, local social enterprise and commissioners working to achieve personalisation and build community capacity for seldom heard groups.

Recommendations

- Adult social care support services being developed within the policy frameworks of equality and personalisation need to be responsive to diverse communities and particular populations. This includes the groups explored in this review: BME people, LGB people, refugees and asylum seekers and people from faith communities.
- Local specialist and community support organisations can offer cultural intelligence, opportunities for self-help/mutual support, a collective voice, social and emotional support and broader and more holistic understandings of support.

Such organisations need investment in terms of funding but also capacity building and skills development for sustainability.

- Processes (including those for commissioning and funding) and regulation need to be proportionate and accessible for small community-based providers.
- There is a tradition of compensatory self-organisation, use of informal networks and a mobilisation of social capital for all these groups in response to marginalisation from mainstream, statutory services. This requires recognition and nurturing in ways that do not stifle its unique nature.
- Marginalisation is characterised by fear of discrimination and loss of control, experience of inappropriate support, concern about stigma and communication difficulties. Specialist and community-based micro-providers can contribute to a wider range of choices for people who feel larger, mainstream services are not suitable or accessible.
- Large mainstream services should not abdicate responsibility for providing culturally sensitive, accessible support to local specialist and community organisations. However, there are potential opportunities for shared learning and development between the two. Specialist and community organisations can help seldom heard people engage with mainstream services and reduce stigma.
- Micro-provider, local social enterprise and community interest company business models have potential for the further development and sustainability of specialist and community support organisations for BME people, LGB people, refugees and asylum seekers and people from faith communities.

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